
What is Ehlers-Danlos Syndrome?

Ehlers-Danlos Syndrome (EDS) is a condition that is as black and white as the zebra ribbon that symbolizes the condition. Individuals with the condition are considered medical zebras because of how the condition mimics other conditions. At one time, EDS was considered to be rare; however, now it is considered to be underdiagnosed. Due to awareness and ongoing professional programs, recognition of EDS is improving.

EDS is caused by a defect in the structure, production, or processing of collagen or proteins that interact with collagen, such as mutations in the COL5A or COL3A genes. Not all mutations have been identified for all the subtypes of EDS.

Individuals who are affected by this genetic connective tissue disorder can exhibit many signs such as joint hypermobility, fragile or soft skin, elastic skin, chronic fatigue and pain, spinal issues, neuropathic pain, joint instability, tendon ruptures, easy or unexplained bruising, chronic headaches, arterial dissection, easy bleeding, unexplained fractures and dislocations, and more. Because of these symptoms, this genetic disorder can be a life altering or deadly condition.

Not all who have EDS are affected the same way, which causes it to be misunderstood and underdiagnosed.

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About CEDSA

Center for Ehlers-Danlos Syndrome Alliance (CEDSA) is founded on the principals that children are our future and individuals with EDS need a strong supportive voice to improve their medical care, education, rights, and overall quality of life.

CEDSA works to help parents understand issues and treatment options for their children with EDS. We work with schools to find resolutions to education issues.

CEDSA advocates are driven to ensure justice for parents who have been wrongfully accused of child abuse and educate agencies as to why EDS is not child abuse.

CEDSA's Board of Directors believes that all of our volunteers, medical and professional advisors, and associate consultants work as a team. The wonderful volunteers are the hub of the team! They truly make a difference by providing the coping and success tools to improve life with EDS.

As a non-profit organization, CEDSA relies on the generosity of others and fundraising awareness events in order to provide the multitude of programs that help individuals with EDS and other co-morbid conditions. See our website for the complete list of programs and services that CEDSA offers.

Center for Ehlers Danlos Syndrome Alliance

4805 Hospital Dr. Cass City MI 48726
Telephone: (989) 872-3372
staff@cedsa.org www.CEDSA.org
www.facebook.com/CEDSAorg

IEP plans vs. Section 504 plans

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Individualized Education Plans IDEA Law

The Individuals with Disabilities Education Act (IDEA) is a federal law ensuring services to children with disabilities. IDEA governs how states and public agencies provide early intervention, special education and related services to children and youth with disabilities.

Adhering to the IDEA is accomplished through an Individualized Education Program (IEP). The IEP enables a student with EDS to be classified into one of fifteen possible disability categories. Students with EDS typically are eligible under the following categories: Orthopedic Impairment (OI), Other health impairment (OHI), and Multiple Disabilities (MD); the latter two (OHI/MD) are when students with EDS have more than one disabling condition affecting access to the general education curriculum.

When trying to determine eligibility a student, the Multidisciplinary Evaluation Team (MET) reviews the data to determine what disability impacts the student the most.

Determining whether or not the student's disability impacts his/or her access to the "General Education Curriculum" is the first step in obtaining an IEP. The student's grades/intelligence is not a factor.



How a student with EDS can qualify for an IEP

Each student with EDS is affected differently by the condition; therefore, the potential educational impact and need for support will vary from one student to the next. Listed below are some of the more common manifestations of **EDS** that are valid reasons for writing an IEP:

- Frequent absences and tardiness
- Modified school day
- Chronic Pain, Fatigue, and Headaches
- Visual tracking and convergence issues
- Executive function issues
- Non-Verbal Learning Disorder
- Anxiety, Stress, and Depression
- Writing issues and quality of work
- Length of time to do assignments
- Reading comprehension
- Speech and language impairment
- Attention issues
- Sensory sensitivities
- Dyslexia, Dyscalculia, Word Blindness

An IEP offers more support and services for students with disabilities and can offer more than a limited Section 504 plan.

The majority of students with Ehlers-Danlos Syndrome qualify for an IEP under Otherwise Health Impairment, including those with Specific Learning Disorder!

Section 504 Plans ADA Law

The Americans with Disabilities Act (ADA) allows those with an identified disability access to public and some private institutions equal access as their non-disabled peers; however, these accommodations and modifications must not place undue hardship on or extensive cost to the establishment.

When one looks to apply this to an educational institute, it allows a student the right to access the buildings, classrooms, and to participate in programs without barriers.

The barriers from EDS can be as follows:

- Cannot walk long distances
- Cannot climb stairs
- Cannot sit in certain chairs
- The student cannot carry weight

NEVER can a Section 504 plan modify the General Curriculum to accommodate a student with a disability. If modifications need to be made to the general education curriculum, then an IEP is warranted.

Section 504 plan can implement Special Education Services, which helps the student access the school and programs but it cannot alter the curriculum.